Complete Summary

GUIDELINE TITLE

Clinical practice guidelines for quality palliative care.

BIBLIOGRAPHIC SOURCE(S)

Clinical practice guidelines for quality palliative care. Brooklyn (NY): National Consensus Project for Quality Palliative Care; 2004. 67 p. [1463 references]

GUIDELINE STATUS

This is the current release of the guideline.

COMPLETE SUMMARY CONTENT

SCOPE
METHODOLOGY - including Rating Scheme and Cost Analysis
RECOMMENDATIONS
EVIDENCE SUPPORTING THE RECOMMENDATIONS
BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS
QUALIFYING STATEMENTS
IMPLEMENTATION OF THE GUIDELINE
INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES
IDENTIFYING INFORMATION AND AVAILABILITY
DISCLAIMER

SCOPE

DISEASE/CONDITION(S)

Chronic, debilitating, and life-threatening illness

GUIDELINE CATEGORY

Counseling
Evaluation
Management

CLINICAL SPECIALTY

Family Practice
Geriatrics
Internal Medicine
Nursing

Nutrition
Pediatrics
Psychiatry
Psychology

INTENDED USERS

Advanced Practice Nurses
Allied Health Personnel
Dietitians
Health Care Providers
Hospitals
Managed Care Organizations
Pharmacists
Physician Assistants
Physicians
Psychologists/Non-physician Behavioral Health Clinicians
Social Workers
Utilization Management

GUIDELINE OBJECTIVE(S)

- To facilitate the development and continuing improvement of clinical palliative care programs providing care to patients and families with life-threatening or debilitating illness
- To establish uniformly accepted definitions of the essential elements in palliative care that promote quality, consistency and reliability of these services
- To establish national goals for access to quality palliative care
- To foster performance measurement and quality improvement initiatives in palliative care services
- To foster continuity of palliative care across settings (home, residential care, hospital, hospice)

TARGET POPULATION

- Patients of all ages with life-threatening or debilitating illness, defined as a persistent or recurring condition that adversely affects daily functioning or will predictably reduce life expectancy, including the following patient groups:
  - Children and adults with congenital injuries or conditions leading to dependence on life-sustaining treatments and/or long-term care by others for support of the activities of daily living
  - Persons of any age with acute, serious, and life-threatening illnesses (such as severe trauma, leukemia or acute stroke), where cure or reversibility is a realistic goal, but the conditions themselves and their treatments pose significant burdens
  - Persons living with progressive chronic conditions (such as peripheral vascular disease, malignancies, chronic renal or liver failure, stroke with significant functional impairment, advanced heart or lung disease, frailty, neurodegenerative disorders and dementia).
  - Persons living with chronic and life-limiting injuries from accidents or other forms of trauma

- Seriously and terminally ill patients (such as persons living with end-stage dementia, terminal cancer, or severe disabling stroke), who are unlikely to recover or stabilize, and for whom intensive palliative care is the predominant focus and goal of care for the time remaining
- Family members or other individuals who provide support and with whom the patient has a significant relationship

INTERVENTIONS AND PRACTICES CONSIDERED

Structure and Processes of Care

1. Establishing plan of care based on a comprehensive interdisciplinary assessment of the patient and family
2. Development of a care plan based on the identified and expressed values, goals, and needs of patient and family, with professional guidance and support for decision-making
3. Provision of services to patient and family consistent with care plan
4. Training and supervision of volunteers; support for education and training of interdisciplinary team
5. Incorporation of quality improvement practices within the palliative care program
6. Provision of emotional support to staff and volunteers
7. Establishment of relationship with hospices or other community resources
8. Providing physical environment that meets the preferences and needs of patient and family

Physical Aspects of Care

1. Management of pain, symptoms, and side effects of treatment, including ongoing assessment of pain and symptoms
2. Referral to specialists, as appropriate
3. Patient and family education in disease process and its management

Psychological and Psychiatric Aspects of Care

1. Regular, ongoing assessment of psychological and psychiatric reactions
2. Pharmacological and nonpharmacological management of psychological/psychiatric distress
3. Referral, as appropriate
4. Family education and support
5. Providing grief and bereavement program to patients and families

Social Aspects of Care

1. Assessment of social needs of patients and families
2. Development of care plan responsive to social needs
3. Referral to appropriate social services

Spiritual, Religious, and Existential Aspects of Care

1. Provision of ongoing spiritual, religious, and existential assessments

2. Facilitation of religious and spiritual needs of patient and families, including access to clergy

Cultural Aspects of Care

1. Assessment and provision of culture-specific needs of patients and families
2. Recruitment and hiring practices reflecting cultural diversity of the community

Care of the Imminently Dying Patient

Recognizing and communicating signs and symptoms of impending death and providing care appropriate to patient and family

Ethical and Legal Aspects of Care

Consideration of the legal and ethical aspects of medical decision-making, including advance care directives

MAJOR OUTCOMES CONSIDERED

Not stated

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METHODOLOGY

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METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Hand-searches of Published Literature (Secondary Sources)
Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

All participants in the National Consensus Project (NCP) were invited to suggest key references. Participants also conducted a variety of literature searches in Medline and the Cochrane Collaboration and reviewed many articles and textbooks, primarily in the fields of medicine and nursing. Where experimental evidence of good quality care exists, it is cited. Other references reflect the expert opinion of consensus efforts, professional organizations, and experts in the field. The guideline document does not represent an exhaustive review of the literature relevant to hospice and palliative care. For the Introduction and Domain 1: Structure and Processes of Care, which address fundamental features of palliative care, thorough documentation is provided, while in the sections on physical or psychological distress, key articles or recent summaries that complement the many excellent textbooks on palliation are cited under General References in the original document.

NUMBER OF SOURCE DOCUMENTS

Not stated

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Not stated

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

METHODS USED TO ANALYZE THE EVIDENCE

Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

The National Consensus Project (NCP) has been structured to maximize the participation and input of a broad range of palliative care professionals, health care organizations, policy and standard-setting bodies, consumers, and payers. To this end, a series of working groups has been formed to ensure a comprehensive, transparent, and representative consensus process underpinning the development of Clinical Practice Guidelines for Palliative Care.

Consortium Organizations for the NCP: Based on recommendations from the broader palliative care community, five key national palliative care organizations formed a consortium to oversee and ensure the success of the National Consensus Project. The consortium includes:

- American Academy of Hospice and Palliative Medicine
- Center to Advance Palliative Care
- Hospice and Palliative Nurses Association
- Last Acts Partnership
- National Hospice and Palliative Care Organization

Steering Committee: Each of the five consortium organizations has appointed four representatives to a Steering Committee. The Steering Committee was charged with the writing and timely completion of the consensus document, communication and dissemination of progress reports to all appropriate NCP participants, and procurement of the necessary financial support for the project. The committee made all decisions regarding the NCP through a voting process at its regular monthly meetings.

Advisory Committee: An Advisory Committee was established concurrently with the Steering Committee. This group, which includes 96 nationally recognized palliative care leaders nominated by their peers, served as document reviewers and key contributors to document development and revision.

The Steering Committee developed a process for drafting and reviewing the document. The initial steps were as follows:

- The Steering Committee developed an outline that identified the key domains after review of all existing standards and consensus documents and input from the Advisory Committee.
- Clinical practice guidelines were developed based on consensus and the best available scientific evidence.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

Comparison with Guidelines from Other Groups
External Peer Review
Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Comparison with Guidelines from Other Groups

The National Hospice and Palliative Care Organization provided a "cross-walk" of the National Consensus Project (NCP) guidelines with their Standards of Practice for Hospice Programs (2002).

Peer Review

The Steering Committee developed a process for drafting and reviewing the document. The final steps in this process were as follows:

- When more than 70 percent of committee members voted to accept the document, it was distributed to the Advisory Committee for review and rating using the 1–4 scale, and to the five consortium organizations for review by their boards of directors or respective governing bodies.
- Feedback and ratings by the Advisory Committee and consortium organizations were tallied and reviewed by the Steering Committee. Subsequent revisions were reviewed, voted on and approved by the Steering Committee. Unanimity of approval by the boards of all five consortium organizations was required at this stage of document development.

- The document was then distributed to all the liaison organizations for endorsement and assistance in national dissemination of the guidelines.

MAJOR RECOMMENDATIONS

Note from the National Guideline Clearinghouse (NGC): Reference numbers in parentheses refer to the grouped references in the original guideline document and can be accessed at www.nationalconsensusproject.org/guideline3.pdf. For complete citations, readers are referred to the bibliography at www.nationalconsensusproject.org/reference.pdf.

Excellence in specialist-level palliative care requires expertise in the clinical management of problems in multiple domains, supported by a programmatic infrastructure that furthers the goals of care and supports practitioners. Eight domains were identified as the framework for these guidelines: Structure and Processes; Physical Aspects of Care; Psychological and Psychiatric Aspects of Care; Social Aspects of Care; Spiritual, Religious and Existential Aspects of Care; Cultural Aspects of Care; Care of the Imminently Dying Patient; and Ethical and Legal Aspects of Care. These domains were drawn from the work of the previously established Australian, New Zealand, Canadian, Children´s Hospice International, and National Hospice and Palliative Care Organization (NHPCO) standards efforts. (31)

Domain 1: Structure and Processes of Care

Guideline 1.1 The plan of care is based on a comprehensive interdisciplinary assessment of the patient and family. (10, 11)

Criteria:

- Assessment and its documentation are interdisciplinary and coordinated.
- Initial and subsequent assessments are carried out through patient and family interview, review of medical records, discussion with other providers, physical examination and assessment, and relevant laboratory and/or diagnostic tests or procedures. (33)
- Assessment includes documentation of disease status, including diagnoses and prognosis; comorbid medical and psychiatric disorders; physical and psychological symptoms; functional status; social, cultural, spiritual, and advance care planning concerns and preferences, including appropriateness of referral to hospice. (34) Assessment of children must be conducted with consideration of age and stage of neurocognitive development. (35)
- Patient and family expectations, goals for care and for living, (8) understanding of the disease and prognosis, (13) as well as preferences for the type (8) and site of care (20, 26) are assessed and documented.
- The assessment is reviewed on a regular basis. (36)

Guideline 1.2 The care plan is based on the identified and expressed values, goals and needs of patient and family (8), **and is developed with professional guidance and support for decision-making.** (9)

Criteria:

- The care plan is based upon an ongoing assessment, determined by goals set with patient and family, and with consideration of the changing benefit/burden assessment at critical decision points during the course of illness. (8)
- The care plan is developed through the input of patient, family, caregivers, involved health care providers, and the palliative care team with the additional input, when indicated, of other specialists (37) and caregivers, such as school professionals, clergy, friends, etc. (38)
- Care plan changes are based on the evolving needs and preferences of the patient and family over time, and recognize the complex, competing, and shifting priorities in goals of care. (36)
- The interdisciplinary team coordinates and shares the information, provides support for decision-making, develops and carries out the care plan, and communicates the palliative care plan to patient and family, to all involved health professionals, and to the responsible providers when patients transfer to different care settings. (13, 15)
- Treatment and care setting alternatives are clearly documented and communicated and permit the patient and family to make informed choices. (8, 13)
- Treatment decisions are based on goals of care, assessment of risk and benefit, best evidence, and patient/family preferences. Re-evaluation of treatment efficacy and patient-family preferences is documented. (36, 39)
- The evolving care plan must be clearly documented over time. (39)

Guideline 1.3 An interdisciplinary team provides services to the patient and family, consistent with the care plan.

Criteria:

- Specialist-level palliative care is delivered by an interdisciplinary team. (11)
- The team includes palliative care professionals with the appropriate patient population-specific education, credentialing and experience, and ability to meet the physical, psychological, social, and spiritual needs of both patient and family. (14) Of particular importance is hiring physicians, nurses, and social workers appropriately trained and ultimately certified in hospice and palliative care.
- The interdisciplinary palliative care team involved in the care of children, either as patients or as the children of adult patients, has expertise in the delivery of services for such children. (35)
- The patient and family have access to palliative care expertise and staff 24 hours per day, seven days per week. (40)
- Respite services are available for the families and caregivers of children or adults with life-threatening illnesses. (41)
- The interdisciplinary team communicates regularly (at least weekly, more often as required by the clinical situation) to plan, review, and evaluate the care plan, with input from both patient and family. (42)
- The team meets regularly to discuss provision of quality care, including staffing, policies, and clinical practices. (42)
- Team leadership has appropriate training, qualifications, and experience. (43)

- Policies for prioritizing and responding to referrals in a timely manner are documented. (44)

Guideline 1.4 The interdisciplinary team may include appropriately trained and supervised volunteers. (45)

Criteria:

- If volunteers participate, policies and procedures are in place to ensure the necessary education of volunteers, and to guide recruitment, screening, training, work practices, support, supervision, and performance evaluation, and to clarify the responsibilities of the program to its volunteers.
- Volunteers are screened, educated, coordinated, and supervised by an appropriately educated and experienced professional team member.

Guideline 1.5 Support for education and training is available to the interdisciplinary team.

Criteria:

- Educational resources and continuing professional education focused on the domains of palliative care contained in this document are regularly provided to staff, and participation is documented. (46)

Guideline 1.6 The palliative care program is committed to quality improvement in clinical and management practices. (17)

Criteria:

- The palliative care program must be committed to the pursuit of excellence and the highest quality of care and support for all patients and their families. Determining quality requires regular and systematic measurement, analysis, review, evaluation, goal setting, and revision of the processes and outcomes of care provided by the program.
- Quality care must incorporate attention at all times to:
    - Safety and the systems of care that reduce error
    - Timeliness: care delivered to the right patient at the right time.
    - Patient-centered care, based on the goals and preferences of the patient and the family
    - Beneficial and/or effective care, demonstrably influencing important patient outcomes or processes of care linked to desirable outcomes
    - Equity: care that is available to all in need and who could benefit
    - Efficiency: care designed to meet the actual needs of the patient so that it does not waste resources
- The palliative care program establishes quality improvement policies and procedures.
- Quality improvement activities are routine, regular, reported and are shown to influence clinical practice.
- The clinical practices of palliative care programs reflect the integration and dissemination of research and evidence of quality improvement.

- Quality improvement activities for clinical services are collaborative, interdisciplinary, and focused on meeting the identified needs of patients and their families.
- Patients, families, health professionals, and the community may provide input for evaluation of the program.

Guideline 1.7 The palliative care program recognizes the emotional impact on the palliative care team of providing care to patients with life-threatening illnesses and their families. (47)

Criteria:

- Emotional support is available to staff and volunteers as appropriate.
- Policies guide the support of staff and volunteers, including regular meetings for review and discussion of the impact and processes of providing palliative care.

Guideline 1.8 Palliative care programs should have a relationship with one or more hospices and other community resources in order to ensure continuity of the highest-quality palliative care across the illness trajectory. (38)

Criteria:

- Palliative care programs must support and promote continuity of care across settings and throughout the trajectory of illness.
- As appropriate, patients and families are routinely informed about and offered referral to hospice and other community-based health care resources.
- Referring physicians and health care providers are routinely informed about the availability and benefits of hospice and other community resources for care for their patients and families as appropriate and indicated.
- Policies for formal written and verbal communication about all domains in the plan of care are established between the palliative care program, hospice programs, and other major community providers involved in the patients´ care. Policies enable timely and effective sharing of information among teams while safeguarding privacy.
- Where possible, hospice and palliative care program staff routinely participate in each other´s team meetings to promote regular professional communication, collaboration, and an integrated plan of care on behalf of patients and families.
- Palliative and hospice care programs, as well as other major community providers, routinely seek opportunities to collaborate and work in partnership to promote increased access to quality palliative care across the continuum.

Guideline 1.9 The physical environment in which care is provided should meet the preferences, needs, and circumstances of the patient and family to the extent possible.

Criteria:

- When feasible, care is provided in the setting preferred by the patient and their family. (19, 20)
- When care is provided away from the patient´s home, the care setting addresses safety and, as appropriate and feasible, flexible or open visiting hours, space for families to visit, rest, eat or prepare meals, and meet with the palliative care team and other professionals, as well as privacy and other needs identified by the family. (48) The setting should address the unique care needs of children as patients, family members, or visitors. (35)

Domain 2: Physical Aspects of Care

Guideline 2.1 Pain, other symptoms, and side effects are managed based upon the best available evidence, which is skillfully and systematically applied. (32)

Criteria:

- The interdisciplinary team includes professionals with specialist-level skill in symptom control (11, 14).
- Regular, ongoing assessment of pain, nonpain symptoms (including but not limited to shortness of breath, nausea, fatigue and weakness, anorexia, insomnia, anxiety, depression, confusion, and constipation), treatment side effects, and functional capacities are documented. (49-79) Validated instruments, where available, should be used. (80) Symptom assessment in children and cognitively impaired patients should be performed with appropriate tools. (35)
- The outcome of pain and symptom management is the safe and timely reduction of pain and symptom levels, for as long as the symptom persists, to a level that is acceptable to the patient.
- Response to symptom distress is prompt and tracked, through documentation in the medical record. (39, 51)
- Barriers to effective pain management should be recognized and addressed, including inappropriate fears of the risks of side effects, addiction, respiratory depression, and hastening of death in association with opioid analgesics. (49-51)
- A risk management plan should be implemented when controlled substances are prescribed for long-term symptom management.
- Patient understanding of disease and its consequences, symptoms, side effects of treatments, functional impairment, and potentially useful treatments is assessed. The capacity of the patient to secure and accept needed care and to cope with the illness and its consequences is assessed. (13) (See Domain 3: Psychological and Domain 8: Ethics).
- Family understanding of the disease and its consequences, symptoms, side effects, functional impairment and treatments is assessed. The capacity of the family to secure and provide needed care and to cope with the illness and its consequences is assessed. (13, 21)
- Treatment of distressing symptoms and side effects incorporates pharmacological, nonpharmacological, and complementary/supportive therapies. (78, 79) Approach to the relief of suffering is comprehensive, addressing physical, psychological, social, and spiritual aspects. (10) (See especially Domain 3: Psychological and Domain 4: Social Support).

- Referrals to health care professionals with specialized skills in symptom management are made available when appropriate (e.g., radiation therapists, anesthesia pain management specialists, orthopedists, physical and occupational therapists, child life specialists). (37)
- Family is educated and supported to provide safe and appropriate comfort measures to the patient. Family is provided with backup resources for response to urgent needs. (See Domain 3: Psychological and Domain 4: Social Support).
- A process for quality improvement and review of physical and functional assessment and effectiveness of treatment is documented and leads to change in clinical practice. (17)

Domain 3: Psychological and Psychiatric Aspects of Care

Guideline 3.1 Psychological and psychiatric issues are assessed and managed based upon the best available evidence, which is skillfully and systematically applied. (32, 81)

Criteria:

- The interdisciplinary team includes professionals with patient-specific skill and training in the psychological consequences and psychiatric comorbidities of serious illness for both patient and family, (82) including depression, (55) anxiety, (53) delirium, (54) and cognitive impairment. (68, 84) (See Domain 2: Physical Aspects of Care).
- Regular, ongoing assessment of psychological reactions (83) (including but not limited to stress, anticipatory grieving, and coping strategies) and psychiatric conditions occurs and is documented. (36) Whenever possible, a validated and context-specific assessment tool should be used. (80, 84, 85)
- Psychological assessment includes patient understanding of disease, symptoms, side effects and their treatments, as well as assessment of caregiving needs, capacity, and coping strategies. (13, 81, 83, 86)
- Psychological assessment includes family understanding of the illness and its consequences for the patient as well as the family; assessment of family caregiving capacities, needs, and coping strategies. (13, 21, 81, 83, 84, 87)
- Family is educated and supported to provide safe and appropriate psychological support measures to the patient. (21, 87)
- Pharmacologic, nonpharmacologic, and complementary therapies are employed in the treatment of psychological distress or psychiatric syndromes, as appropriate. (84) Treatment alternatives are clearly documented and communicated and permit the patient and family to make informed choices. (13)
- Response to symptom distress is prompt and tracked, through documentation in the medical record. Regular reevaluation of treatment efficacy and patient-family preferences is documented. (36)
- Referrals to health care professionals with specialized skills in age-appropriate psychological and psychiatric management are made available when appropriate (e.g., psychiatrists, psychologists, and social workers). Identified psychiatric comorbidities in family or caregivers are referred for treatment. (37)

- Developmentally appropriate assessment and support is provided to pediatric patients, their siblings, and the children or grandchildren of adult patients. (35)
- Communication with children and cognitively impaired individuals occurs using verbal, nonverbal, and/or symbolic means appropriate to developmental stage and cognitive capacity.
- Treatment decisions are based on goals of care, assessment of risk and benefit, best evidence, and patient/family preferences. The goal is to address psychological needs, treat psychiatric disorders, promote adjustment, and support opportunities for emotional growth, healing, reframing, completion of unfinished business, and support through the bereavement period. (83-87)
- A process for quality improvement and review of psychological and psychiatric assessment and effectiveness of treatment is documented and leads to change in clinical practice. (17)

Guideline 3.2 A grief and bereavement program is available to patients and families, based on the assessed need for services. (88)

Criteria:

- The interdisciplinary team includes professionals with patient-population-appropriate education and skill in the care of patients and families experiencing loss, grief, and bereavement. (14, 89)
- Bereavement services are recognized as a core component of the palliative care program. (88, 90-93)
- Bereavement services and follow-up are made available to the family for at least 12 months, or as long as is needed, after the death of the patient. (93)
- Grief and bereavement risk assessment is routine, developmentally appropriate, and ongoing for the patient and family throughout the illness trajectory, recognizing issues of loss and grief in living with a life-threatening illness. (92)
- Clinical assessment is used to identify people at risk of complicated grief and bereavement and its association with depression and comorbid complications, particularly among the elderly. (88, 90, 92, 93)
- Information on loss and grief and the availability of bereavement support services, including those available through hospice and other community programs, is made routinely available to families before and after the death of the patient, as culturally appropriate and desired. (90)
- Support and grief interventions are provided in accordance with developmental, cultural, and spiritual needs, expectations, and preferences of the family, including attention to the needs of siblings of pediatric patients and children of adult patients. (91)
- Staff and volunteers who provide bereavement services receive ongoing education, supervision, and support. (47, 94)
- Referrals to health care professionals with specialized skills are made when clinically indicated. (37)

Domain 4: Social Aspects of Care

Guideline 4.1 Comprehensive interdisciplinary assessment identifies the social needs of patients and their families, and a care plan is developed in order to respond to these needs as effectively as possible. (95)

Criteria:

- The interdisciplinary team includes professionals with patient-population-specific skills in the assessment and management of social and practical needs during a life-threatening or chronic debilitating illness. (14)
- Practitioners skilled in the assessment and management of the developmental needs of children should be available for pediatric patients and the children of adult patients, as appropriate. (35)
- A comprehensive interdisciplinary social assessment is completed and documented, to include: family structure and geographic location; relationships; lines of communication; existing social and cultural networks; perceived social support; medical decision-making; work and school settings; finances; sexuality; intimacy; living arrangements; caregiver availability; access to transportation; access to prescription and over-the-counter medicines and nutritional products; access to needed equipment; community resources including school and work settings; and legal issues. (8, 9, 12, 13, 20, 21, 35, 36, 38, 96-100) (See Domain 6: Culture).
- Routine patient and family meetings (101) are conducted with members of the interdisciplinary team to assess understanding and address questions, provide information and help with decision-making, discuss goals of care and advance care planning, determine wishes, preferences, hopes and fears, provide emotional and social support, and enhance communication.
- The social care plan is formulated from a comprehensive social and cultural assessment and reassessment, and reflects and documents values, goals and preferences as set by patient and family over time. (8, 20) Interventions are planned to minimize adverse impact of caregiving on the family and to promote caregiver and family goals and well-being. (21)
- Referrals to appropriate services are made that meet identified social needs and promote access to care, help in the home, school or work, transportation, rehabilitation, medications, counseling, community resources, and equipment. (38)

Domain 5: Spiritual, Religious and Existential Aspects of Care (102, 103)

Guideline 5.1 Spiritual and existential dimensions are assessed and responded to based upon the best available evidence, which is skillfully and systematically applied. (32, 104)

Criteria:

- The interdisciplinary team includes professionals with skill in assessing (14, 104) and responding (105) to the spiritual and existential issues that pediatric and adult patients with life-threatening illnesses and conditions, and their families, are likely to confront.
- Regular, ongoing exploration (104) of spiritual and existential concerns occurs and is documented (including but not limited to life review, assessment of hopes and fears, meaning, purpose, beliefs about afterlife, guilt, forgiveness and life completion tasks). (39) Whenever possible a standardized instrument should be used. (80)
- A spiritual assessment is utilized to identify religious or spiritual/existential background, preferences, and related beliefs, rituals, and practices of the patient and family. (106, 107)

- Periodic reevaluation of the impact of spiritual/existential interventions and patient-family preferences is documented. (36)
- Spiritual/existential care needs, goals, and concerns are addressed (8, 103, 104) and documented, and support is offered for issues of life completion (104) in a manner consistent with the individual´s and family´s cultural and religious values. (106)
- Pastoral care and other palliative care professionals facilitate contacts with spiritual/religious communities, groups, or individuals, as desired by the patient and/or family. Patients have access to clergy in their own religious traditions. (107)
- Professional and institutional use of religious symbols is sensitive to cultural and religious diversity. (107)
- The patient and family are encouraged to display their own religious/spiritual symbols. (107)
- The palliative care service facilitates religious or spiritual rituals as desired by patient and family, especially at the time of death. (109)
- Referrals to professionals with specialized knowledge or skills in spiritual and existential issues are made available when appropriate (e.g., to a chaplain familiar with or from the patient´s own religious tradition). (37)
- A process for quality improvement is documented and leads to change in clinical practice. (17)

Domain 6: Cultural Aspects of Care

Guideline 6.1 The palliative care program assesses and attempts to meet the culture-specific needs of the patient and family.

Criteria:

- The cultural background, concerns, and needs of the patient and their family are elicited and documented. (110-112)
- Cultural needs identified by team and family are addressed in the interdisciplinary team care plan. (110-112)
- Communication with patient and family is respectful of their cultural preferences regarding disclosure, truth-telling, and decision-making. (113, 114)
- The program aims to respect and accommodate the range of language, dietary and ritual practices of patients and their families. (79, 114, 115)
- When possible, the team has access to and utilizes appropriate interpreter services. (116)
- Recruitment and hiring practices strive to reflect the cultural diversity of the community. (117)

Domain 7: Care of the Imminently Dying Patient

Guideline 7.1 Signs and symptoms of impending death are recognized and communicated, and care appropriate for this phase of illness is provided to patient and family. (118)

Criteria:

- The patient´s and family´s transition to the actively dying phase is recognized, when possible, and is documented and communicated appropriately to patient, family, and staff. (118)
- End-of-life concerns, hopes, fears, and expectations are addressed openly and honestly (119) in the context of social and cultural customs (120) in a developmentally appropriate manner. (121)
- Symptoms at the end of life are assessed and documented with appropriate frequency (122) and are treated based on patient-family preferences. (8)
- The care plan is revised to meet the unique needs of the patient and family at this phase of the illness. (36) The need for higher intensity and acuity of care during the active dying phase is met and documented.
- Patient and family wishes regarding care setting for the death are documented. (20) Any inability to meet these needs and preferences is reviewed and addressed by the palliative care team.
- As patients decline, the hospice referral option will be introduced (or reintroduced) for those who have not accessed hospice services. (38)
- The family is educated regarding the signs and symptoms of approaching death (13, 118) in a developmentally-, age-, and culturally-appropriate manner. (119-121)

Domain 8: Ethical and Legal Aspects of Care

Guideline 8.1 The patient´s goals, preferences and choices are respected within the limits of applicable state and federal law, and form the basis for the plan of care. (8)

Criteria:

- The interdisciplinary team includes professionals with knowledge and skill in ethical, legal, and regulatory aspects of medical decision-making. (123)
- The patient or surrogate´s expressed wishes, in collaboration with the family and the interdisciplinary team, form the basis for the care plan. (8)
- The adult patient with decisional capacity determines the level of involvement of the family in decision-making and communication about the care plan. (124)
- Evidence of patient preferences for care is routinely sought and documented in the medical record. Failure to honor these preferences is documented and addressed by the team. (8, 34)
- Among minors with decision-making capacity, the child´s views and preferences for medical care, including assent for treatment, should be documented and given appropriate weight in decision-making. When the child´s wishes differ from those of the adult decision-maker, appropriate professional staff members are available to assist the child. (35, 124)
- The palliative care program promotes advance care planning in order to understand and communicate the patient´s or an appropriate surrogate´s preferences for care across the health care continuum. (34)
- When patients are unable to communicate, the palliative care program seeks to identify advance care directives, evidence of previously expressed wishes, values, and preferences, and the appropriate surrogate decision-makers. The team must advocate the observance of previously expressed wishes of the patient or surrogate when necessary. (8, 34, 125)

- Assistance is provided to surrogate decision-makers on the legal and ethical bases for surrogate decision-making, including honoring the patient´s known preferences, substituted judgment, and best interest criteria. (8, 9, 125)

Guideline 8.2 The palliative care program is aware of and addresses the complex ethical issues arising in the care of persons with life-threatening debilitating illness. (123, 126)

Criteria:

- Ethical concerns commonly encountered in palliative care are recognized and addressed, using ethical principles to prevent or resolve ethical dilemmas, including: beneficence, respect for persons and self-determination, and associated regulatory requirements for truth-telling, capacity assessment, confidentiality, assent and permission for persons not of legal age to consent, and informed consent; attention to justice and nonmaleficence, and associated avoidance of conflicts of interest. (123, 126) The team recognizes the role of cultural variation in the application of professional obligations, including truth-telling, disclosure, decisional authority, and decisions to forgo therapy. (See Domain 6: Cultural Considerations). Attention must be paid to the role of children and adolescents in decision-making. (35)
- Care is consistent with the professional codes of ethics, and the scope, standards, and code of ethics of palliative care practice are modeled on existing professional codes of ethics for all relevant disciplines. (128, 129)
- The palliative care team aims to prevent, identify, and resolve ethical dilemmas related to specific interventions such as withholding or withdrawing treatments (including nutrition and hydration), instituting do not resuscitate (DNR) orders, and the use of sedation in palliative care. (127, 130, 131)
- Ethical issues are documented; (39) referrals are made to ethics consultants or a committee, as appropriate. (132)

Guideline 8.3 The palliative care program is knowledgeable about legal and regulatory aspects of palliative care. (123)

Criteria:

- Palliative care practitioners are knowledgeable about legal and regulatory issues, including federal and state statutes and regulations regarding medical decision-making, advance care planning and directives; (123) the roles and responsibilities of surrogate decision-makers; (124, 125) barriers to pain relief, the legal requirements for use of controlled substances and the imperative that regulatory policy not interfere with patient care; (51) pronouncing death; (134, 135) request for autopsy and organ transplant; (136) and associated documentation in the medical record.
- Patients and families are routinely advised of the need to seek professional advice on creating or updating property wills and guardianship agreements. (133)

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The evidence base includes well-designed, useful studies, both observational and experimental, as well as published consensus statements and expert opinions.

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

The widespread adoption of these guidelines in the United States will help establish palliative care as an integral component of the health care of persons with life-threatening and debilitating chronic illness. It is hoped that these Clinical Practice Guidelines for Palliative Care will encourage access to high-quality palliative care that patients and their families can come to expect and rely upon.

POTENTIAL HARMS

Not stated

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

These clinical practice guidelines are not linked to regulatory or reimbursement criteria and are not mandatory. However they are written with the intent that they will be used as guidelines to promote the development of highest-quality clinical palliative care services across the health care continuum.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

In order to ensure the success and effectiveness of the project in improving access to quality palliative care in the United States, a comprehensive communication and dissemination plan for the document was developed. The plan is intended to ensure distribution of the guidelines to organizations, associations, clinicians, managers, providers, policy-makers, educators, researchers and other individuals who plan, provide or assess palliative care programs.

Liaison Organizations: During the process of document creation, a list of liaison organizations was developed. More than 100 organizations with major responsibility for the health care of patients with life-threatening illnesses in the U.S. were asked to offer their endorsement and to assist in the broadest possible national dissemination of the standards.

IOM CARE NEED

End of Life Care
Living with Illness

IOM DOMAIN

Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

Clinical practice guidelines for quality palliative care. Brooklyn (NY): National Consensus Project for Quality Palliative Care; 2004. 67 p. [1463 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2004 May

GUIDELINE DEVELOPER(S)

National Consensus Project - Disease Specific Society

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American Academy of Hospice and Palliative Medicine
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National Hospice and Palliative Care Organization
The Purdue Pharma Fund
The Robert Wood Johnson Foundation

GUIDELINE COMMITTEE

National Consensus Project Steering Committee

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FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

GUIDELINE STATUS

This is the current release of the guideline.

GUIDELINE AVAILABILITY

Electronic copies: Available in Portable Document Format (PDF) from the National Consensus Project Web site.

Print copies: Ordering information is available from the National Consensus Project Web site or through the National Hospice and Palliative Care Organization Marketplace by calling (800) 646-6460.

AVAILABILITY OF COMPANION DOCUMENTS

None available

PATIENT RESOURCES

None available

NGC STATUS

This NGC summary was completed by ECRI on August 4, 2004. The information was verified by the guideline developer on August 16, 2004.

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